SCIRE

SPINAL CORD INJURY REHABILITATION EVIDENCE

Primary Care for People Following Spinal Cord Injury

Karen Smith, MD, FRCPC
Mary Ann McColl, PhD, MTS
Alice Aiken, PhD
Alexander (Sandy) McColl, MD

icord
Rick Hansen Institute
Institut Rick Hansen
Ontario Neurotrauma Foundation
Fondation ontarienne de neurotraumatologie
LAWSON HEALTH RESEARCH INSTITUTE
Aging, Rehabilitation & Geriatric Care
Western
UBC
G.F. STRONG REHAB CENTRE
A part of the Vancouver Coastal Health Authority
ST JOSEPH's HEALTH CARE
LONDON

www.scireproject.com
Version 5.0

Key points

A large majority of people with spinal cord injuries (SCI) have a family doctor and are satisfied with care received.

People with spinal cord injuries tend to be high users of primary care. Many people with SCI receive their primary care from a physiatrist or other specialist.

Lack of SCI-specific knowledge is a significant problem for people with SCI in primary care. There is evidence for inadequate knowledge of important secondary conditions and lack of adherence to clinical guidelines in treating SCI patients.

Physical barriers are also encountered in some primary care practices.

The majority of the issues raised by SCI patients in primary care are disability-related – specifically, they are secondary complications of the spinal cord injury.

There is a high level of consistency in the literature on the most common issues raised by people with spinal cord injuries in primary care.

The most commonly raised issues are bowel, bladder and pain. Also of significant concern are skin care, equipment and medication needs, depression and bone density.

Unmet health needs are a significant problem for people with SCI in primary care, with information needs in particular being poorly met.

There is evidence for the effectiveness of outreach programs for maintaining health among patients with SCI. In particular, web-based and telephone-based technologies show promise in this area.

Table of Contents

Abbreviations i
1.0 Introduction 1
2.0 Access and Utilization Issues for Primary Care of Adults with SCI 2
3.0 Outreach Programs 9
4.0 Health Issues of Key Importance in Primary Care for SCI 14
5.0 General Discussion and Implications 21
6.0 Summary 22
7.0 References 25

Smith K, McColl MA, Aiken A, McColl A (2014). Primary Care for People with SCI. In Eng JJ, Teasell RW, Miller WC, Wolfe DL, Townson AF, Hsieh JTC, Connolly SJ, Noonan VK, Loh E, McIntyre A, editors. Spinal Cord Injury Rehabilitation Evidence. Version 5.0. Vancouver: p 1- 28.

Abbreviations

AD	autonomic dysreflexia
AE	assistive equipment
ARI	acute respiratory infection
BPI	Brief Pain Inventory
CPG	clinical practice guideline
CPHE	Comprehensive Preventative Health Evaluation
COPD	chronic obstructive pulmonary disorder
CVD	cardiovascular disease
ED	emergency department
EM	emergency medicine
FD	family doctor
FFS	fee for service
FIM	Functional Independence Measure
GP	general practitioner
HCQ	Health Care Questionnaire
HR	hazard ratio
PCP	primary care physician
PHQ-9	Patient Health Questionnaire-9
PM	prescription medications
PM&R	physical medicine and rehabilitation
PR	physical rehabilitation
PSHCPS	Patient Satisfaction with Health Care Provider Scale
MCO	managed care organization
MI	mental illness
MPQ	McGill Pain Questionnaire
MRI	magnetic resonance imaging
NTSCI	non-traumatic SCI
OB/GYN	obstetrician gynecologist
RIO	Rurality Index of Ontario
SC	specialist care
SCIM	Spinal Cord Independence Measure
SF	short form
SIS	spinal injury specialist
TBI	traumatic brain injury
TSCI	traumatic spinal cord injury
VA	veteran affairs
VO_2	peak oxygen uptake
YPI	years post-injury

Primary Care for People
Following Spinal Cord Injury

1.0 Introduction

Primary care has been shown worldwide to be one of the most significant factors in maintaining the health of individuals and populations (Starfield 1997). In recent years, there has been a renewal and reshaping of primary care around the world with an unprecedented emphasis on funding models, accessibility and quality. In the last decade, there has been an increased interest in the role and effectiveness of primary care in spinal cord injury; however in most typical primary care practices, there are only a handful of patients with spinal cord injuries, and there is considerable uncertainty among family physicians about how to provide people with SCI with an optimal standard of care (Holcomb 2008; McColl et al. 2008; Middleton 2008; Potter 2004; Stanley 1981).

Family physicians play a key role in maintaining the health of people with spinal cord injuries. According to Bluestein (1988), family physicians play an important coordinating role, acting as a link between the SCI patient and multiple health care providers. The family physician also acts as a patient advocate, authorizer for needed services and benefits, and as a central clearinghouse for information. Kroll and Neri (2008) and Holcomb (2008) discuss the essential role that family physicians play in health maintenance and promotion for patients with SCI, particularly with regard to routine age and sex-appropriate preventive health care. Family physicians are often conflicted in the expectation that they will provide a gatekeeper role in the health care system (Batavia, 1999). They are simultaneously expected to be the patient's carer, supporter and advocate, while at the same time screening patients for access to specialists, programs and benefits.

Primary care is good, economical, holistic care, but the literature suggests that family medicine does not serve patients with SCI as well as other patients. People with SCI report that family physicians typically lack the specific expertise necessary to provide them with optimal primary care (Kroll et al. 2003; Batavia 1999; Tolbert 2002; Stanley 1981). Several approaches have been tried to remedy this problem. Some authors favour multidisciplinary approaches, where nurses and other rehabilitation specialists work in collaboration with the family physician. Bernardez (1994) recommends specially trained physician assistants; however, physician assistants are neither available nor registered to practice in many countries outside of the US. Holcomb (2008) recommends specialist community-based nurses as adjuncts to family physician care. Of note, he argues against using specialists (such as physiatrists) as primary care providers for the SCI patient because of scarcity, geographical mal-distribution, and lack of training in health promotion and illness prevention. A number of articles have been written as primers to family physicians who may have a patient with a spinal cord injury in their practice (Tepperman 1989; Stanley 1981; Middleton et al. 2008a & b; Brooker 1999; McColl et al, 2012). Groah (2002) offers a self-training module with 4 case studies, and Mann, Middleton and Leong (2007) offer an assessment tool for improving health care for people with SCI.

This review outlines empirical evidence regarding primary care for adults with SCI. In order to develop a more comprehensive analysis of this material, the methods used expand upon those traditionally used for the other SCIRE reviews (see SCIRE Methods). Specifically, two new databases with a focus on the social sciences were searched (Social Sciences Abstracts, and Social Work Abstracts), and the inclusion criteria was broadened to include any relevant qualitative studies.

This literature has been divided into three subsections: 1) access and utilization; 2) outreach program; and 3) health issues.

2.0 Access and Utilization Issues for Primary Care of Adults with SCI

Access to primary care has been a key health issue in many jurisdictions in recent years. When the media refer to access, they usually mean issues like wait times, geographical distribution and supply of providers; however, for people with spinal cord injuries, there is another layer of access issues. People with SCI encounter four types of barriers to optimal primary care: physical, knowledge-based, attitudinal and systemic (McColl et al. 2009). These barriers affect the simple ability to enter and use the facilities of the practice, and the ability to receive an appropriate standard of care. Whereas access issues may delay and inconvenience patients in the general population, for patients with disabilities, access issues can actually prevent care. This section summarizes the findings of 16 studies that provide information on access and utilization of primary care among adults with SCI.

Table 1: Access and Utilization Issues for Primary Care of Adults with SCI

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
Guilcher et al. 2013 Canada Retrospective Cohort N=1217	**Population**: Individuals with TSCI admitted to Ontario hospitals between April 2003 and March 2009 **Treatment**: No treatment **Purpose**: To describe patterns of ED visits made by persons with TSCI **Outcome Measures:** Visits classified as potentially preventable, low acuity, high acuity.	1. 752 (17%) of visits were classified as potentially preventable, 33% low acuity, 50% high acuity 2. Regardless of acuity level, most patients did not see a GP the day of the ED visit
Hagen et al. 2012 Norway Observational (Survey) N=105	**Population:** Patients with TSCI injured between 1982 and 2001 in western Norway; mean age at injury 37.6 years; time since injury 11.9 years; 80.0% male **Treatment:** No treatment **Purpose:** To examine how satisfied patients with traumatic spinal cord injury are with their general practitioners. **Outcome Measures:** Self-report satisfaction on the following domains: availability, understandable, easy to ask, understand, knowledge, overall satisfaction	1. Individuals with incomplete injuries were less satisfied than those with complete injuries ($p=0.015$) 2. Patients with traumatic spinal cord injury were more satisfied than the general Norwegian population with their GP ($p<0.001$).
DiPonio et al. 2011 USA Cross-sectional survey N=168	**Population:** 168 emergency medicine (EM) residents **Treatment:** No treatment **Purpose:** to assess knowledge and ability of EM residents to accurately diagnose and treat SCI patients. **Outcome Measures:** 16-item survey of knowledge of autonomic dysreflexia (AD), urinary tract infection, post-traumatic syrinx, gastrointestinal system, pulmonary disturbances and cardiac complications; emergency medicine utilization by veterans with SCI	1. EM residents scored on average 47% on overall knowledge 2. Scores were highest on diagnosis of possible syrinx (90%) and potential consequences of AD (81%) 3. Greatest knowledge deficits in pulmonary physiology; 6% knew how to clear secretions in patient with high thoracic SCI; 2% knew how to optimize pulmonary mechanics in patients with pneumonia
Guilcher et al. 2010 Canada Retrospective Cohort N= 1562	**Population:** 560 participants with traumatic SCI (TSCI) (24.6% F; mean age 46.9±17.3 yrs.); 1002 participants with non-traumatic SCI (NTSCI), (47.8% F; mean age 61.6±15.8 yrs) **Treatment:** No treatment **Purpose:** to compare health care utilization including Emergency Department (ED) use	1. Mean GP visits in first year post discharge: TSCI 12.3; NTSCI 14.7 ($p = 0.03$) 2. Mean ED visits: TSCI 1.3; NTSCI 1.2 (ns) 3. High utilization (> 30 MD visits/yr) related to older age (≥60 years), urban

Author Year; Country Score Research Design Total Sample Size	**Methods**	**Outcome**
	between traumatic and non-traumatic SCI **Outcome Measures:** utilization statistics, level of injury, length of stay in rehabilitation, Functional Independence Measure (FIM), Charlson co-morbidity index, rurality, socioeconomic status	setting and low FIM score. 4. High ED use related to rural setting, low income and low discharge FIM
Yuen et al. 2010; USA Cross-sectional survey N=192	**Population:** 192 SCI (>40.1% F; mean age: 43.9; mean YPI 12.8 yrs) **Treatment:** No treatment. **Purpose:** to explore dental care utilization among adults with SCI **Outcome measures:** Oral Health Survey – self-reported barriers in accessing dental care, perceived need for dental care, tooth-brushing habits, and self-rated condition of teeth.	1. No significant differences in SCI who visited the dentist in the past year compared to general population (65.5% vs. 68.8%, p=.350) 2. 47.9% (n=92) indicated immediate need for dental treatment 3. Most common barriers to accessing dental care was high cost (40.1%), physical barriers (22.9%) 4. No significant difference between paraplegia vs. tetraplegia in utilization of dental services
Munce et al. 2009 Canada Case series N=559	**Population:** 559 adults with SCI (24% F), ≥ 1 yr after acute care; 62 lumbar, 126 thoracic, 350 cervical, 21 other. **Treatment:** No treatment. **Purpose**: To examine physician utilization from various Ontario health databases for the years 2003-2006. **Outcome measures:** physician utilization, including family physician, specialist and emergency department visits; Charlson Index (co-morbidity); Rurality Index of Ontario (RIO).	1. Overall, women had a higher number of physician visits, and men had a higher number of visits to their physiatrist. 2. Older age (70+) (Odds Ratio=3.64), direct discharge to chronic care (OR=3.62) and an in-hospital complication (OR=2.34) were associated with 50 or more physician visits per year. 3. Younger age (OR=0.19) and direct discharge to chronic care (OR=11.52) were associated with 50 or more specialist visits per year. 4. Rural living predicted two or more visits to the ED (OR=2.16)
van Loo et al. 2009 Netherlands Observational (Survey) N = 453	**Population:** Mean age 47.7; (34.9% F); Complete tetraplegia 19.9%, Incomplete tetraplegia 14.4%, Complete paraplegia 46.3%, Incomplete paraplegia 19.4% **Treatment:** No treatment. **Purpose:** To determine the care received for secondary conditions and extra care needs, and to determine if the secondary conditions were preventable. **Outcome measures:** Questionnaire on frequency of SCI-related contacts with professional, secondary conditions and conditions perceived as most important, care received, and how condition could have been prevented.	1. 77% had SCI-related contact with their general physician, 57% with a physiatrist, 65% with another specialist. 2. 72% indicated need for additional care due to secondary conditions. 3. For most important secondary conditions, 47% received care, and extra care in 41.3%. 4. Patients preferred to receive follow-up care from specialists rather than community care.
Donnelly et al. 2007 Canada, US, & UK Observational (Survey) N=373	**Population:** 373 individuals with SCI (15% F); 127 Canadian, 162 British, 84 American; avg age 58, avg duration SCI 34 yrs. **Treatment:** No treatment. **Purpose:** To describe utilization, accessibility	1. 93% had a family doctor (FD), 63% had a spinal injury specialist (SIS), 56% had both, 36% had only a FD, 6% had only a SIS, and 1% had no doctor at all. Canadians most likely to

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
	and satisfaction with primary and preventative health care services by individuals with long term SCI; to compare results across three countries: Canada, US, and UK. **Outcome measures:** 46-item measure [compilation of Health Care Questionnaire (HCQ) and Patient Satisfaction with Health Care Provider Scale (PSHCPS)] of utilization, access and satisfaction with primary and preventative health care services	have received care from FD and Americans from specialists. 2. The highest utilization of FD was for pain (86%, p<0.05) and fatigue (84%, p<0.05); The highest Utilization of SIS was for routine rehab follow-up (91%, p<0.05) 3. FD were more accessible than SIS in all areas, with the exception of physical accessibility of office and equipment. 4. Satisfaction was rated as 74% for FD and 76% for SIS; there were no significant differences in accessibility or satisfaction across countries.
Collins et al. 2005 USA Observational (Survey) N=853	**Population:** 853 veterans with SCI **Treatment:** No treatment. **Purpose**: to assess patient satisfaction with the annual comprehensive preventative health evaluation (CPHE) **Outcome measures:** 21 item questionnaire about satisfaction with CPHE: content, whether needs were met, what respondents valued about the examination and health concerns they would like to see addressed.	1. 76% of survey respondents had completed the CPHE within the previous year. 2. Satisfaction with the CPHE was 81%. Completion of CPHE was related to other health care utilization and having health needs met.
Goetz et al. 2005 USA Pre-post N=4432	**Population:** 4432 subjects (3% F); age: 47-69 yrs; **Treatment:** targeted dissemination & implementation of neurogenic bowel Clinical Practice Guideline. **Purpose:** to determine whether adherence to clinical guidelines could be improved through a targeted implementation strategy. **Outcome measures:** Adherence to CPG before implementation (T1), after publication (T2) and after dissemination and implementation strategies (T3).	1. Overall adherence to recommendations did not change between T1 and T2 2. Statistically significant increase in adherence for 3 of 6 recommendations from T2 to T3 (p<0.001) 3. Publication alone did not alter adherence, targeted implementation increased adherence for 3 of 6 recommendations.
Beatty et al. 2003 USA Observational (Survey) N=800 (169 SCI)	**Population:** 800 adults ≥18 years (69% F) with either arthritis (357), SCI(169), MS(164), or CP (110) **Treatment:** No treatment. **Purpose:** To survey patterns of need for and access to specific health care services; factors predicting access. **Outcome measures:** 80 item self-report questionnaire on perceived need for and access to: primary care physician (PCP); specialist care (SC); physical rehabilitation (PR); assistive equipment (AE); and prescription medications(PM)	1. Overall need for health services varied; 62.7% reported a need for PCP, 57.4% for SC, 39.1% for PR, 69.2% for AE, & 94.1% for PM 2. Need Vs. actual receipt of services: 67% of needed PCP was received; 75.3% of SC; 40.9% of PR; 69.2% of AE; and 93.1% of PM. 3. Factors affecting access: Health plan type [fee for service or managed care organization]; Condition; Health status; Severity; Coverage; Income; Age 4. No differences were found across gender and region of residence
Cox et al. 2001 Australia Observational (Survey)	**Population:** 54 subjects (22% F); age 19-79 yrs; Injury: tetraplegia 30, paraplegia 24. **Treatment:** No treatment	1. 25% indicated high or very-high need for specialist outreach services; 2% saw no need.

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
N=54	**Purpose:** To assess areas of need **Outcome measures:** overall need for specialist multidisciplinary outreach service, most significant barriers to meeting needs, preferred service delivery options; rated on a 5-point scale	2. Barriers: limited local expert knowledge (81%), inadequate funding (56%), complicated process/service fragmentation (31%). 3. Preferred service delivery: telephone advice (79%), home visiting (43%).
Bockeneck 1997 USA Observational (Survey) N=144	**Population:** 144 SCI outpatients (no demographic information stated). **Treatment:** No treatment. **Purpose:** To survey whether primary care needs of outpatient population with SCI were being met. **Outcome measures:** self-reported survey of primary care services, and whether additional services needed in the area of primary care at a rehabilitation facility.	1. 50% of SCI outpatients considered their rehabilitation physician as their primary care physician. 2. Of the SCI patients who had another physician treating general medical problems, 48% were treated by a general practitioner. 3. 96% of SCI patients reported that their physician's office was accessible. 4. 90% of SCI patients reported that they had no difficulty receiving medical care in the community. 5. 51% of SCI patients reported that they would be interested in obtaining all general medical care at one rehabilitation facility.
Glickman et al. 1996 England Observational (Survey) N=139	**Population:** 139 General Practitioners (GPs) with SCI patients **Treatment:** No treatment. **Purpose**: to examine the workload and common problems facing primary care teams in SCI management. **Outcome measures:** Mailed survey inquiring about annual number of consultations with the patient regarding any of gastrointestinal, urological and dermatological problems, and the magnitude of pain and spasticity	1. Average annual consultation rate with: GP in surgery = 4.03 (range = 0 – 52); GP home visit = 4.57 (range = 2 – 26); Other team member in surgery = 0.56 range = 0 – 6); Other team member home visit = 50.94 (range = 0 – 730). 2. 53.9% of the GPs offered services to change urethral catheters; 15.8% were able to change suprapubic catheters; and 29.5% offered psychological or social counselling.
Francisco et al. 1995 USA Observational (Survey) N=104	**Population:** 54 physiatrists and 50 Physical Medicine and Rehabilitation (PM&R) residents (12 in 1st year, 19 in 2nd year, and 19 in 3rd year) **Treatment:** No treatment. **Purpose**: to determine physiatrists' and PM&R residents' opinions on the competency, qualification and desire to provide primary care for the disabled. **Outcome measures:** 4 page, 11- item questionnaire seeking information about: level of training/experience, certification, type of practice/internship; primary care provision by physiatrists.	1. Although 53% believe physiatrists are competent to provide primary care, only 40% were willing to assume the role 2. Only 38% believe that the PM&R residency programs adequately trains physiatrists in primary care for the disabled 3. Conditions for which most respondents believed that primary care should be provided by a physiatrist are SCI (60%), and head injury (51%).
Warms 1987 USA Observational (Survey) N=59	**Population:** 59 adults with SCI (8% F); $\geq$2 years post-injury; age range 21-60. 29 cervical, 24 thoracic, 6 lumbar or sacral injury. **Treatment:** No treatment. **Purpose**: To survey the source and content of health care received by individuals with spinal cord injury and to describe what healthcare services are desired. **Outcome measures:** A self-reported survey	1. 54.2% reported consulting a rehabilitation medicine physician; 44% consulted a family physician.

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
	assessing: source of health care, content of care, and healthcare services desired, but not obtained.	

Discussion

Donnelly and colleagues (2007) and Bockeneck (1997) agree that most people with spinal cord injuries (approximately 90%) have access to primary care; that is, they identify a family physician who is their regular doctor. These results came from surveys of people with long-standing spinal cord injuries in the US, Canada and Great Britain.

In a Dutch sample, van Loo and associates (2009) found that 77% of their community-dwelling sample with spinal cord injuries of average 13 years duration had contacted their family physician in the past year for an issue related to their disability. Glickman and associates (1996), in a survey of primary care providers in England, found that on average, patients with SCI attended their clinics 4 times per year, with an additional 4.5 home visits made by the family doctor, and as many as 51 home visits made by other members of the health care team working out of the primary care setting. This finding highlights the extensive network of community rehabilitation available in the UK. Munce and colleagues (2009), focusing on the Canadian context, found that women with SCI tend to make more visits to their family physician than men; however, very high utilization of primary care (more than 50 visits per year) was related to being over 70 years of age, having significant complications, and living in a chronic care facility.

Bockeneck (1997) surveyed patients attending outpatient clinics in the US, and found that 50% considered their physiatrist as their family physician, and were happy to receive their primary care at the rehabilitation centre. Warms (1987) also found that more than half of community-dwelling adults with SCI in the US received primary care from their physiatrist. In a survey of physiatrists treating patients with spinal cord injuries, Francisco and colleagues (1995) found that only 40% of physiatrists were willing to assume this role, and 53% believed that physiatrists were competent to fulfill this role. Only 38% felt that their residency training had adequately equipped them to provide primary care.

Donnelly and others (2007) found that 63% of their international sample had a spinal cord injury specialist or physiatrist; 56% had both SCI specialist and family doctor, and only 1% had neither. Beatty and colleagues (2003) found that 57% of those surveyed with an SCI reported a need for specialist care, but 25% had unmet needs. With regard to specialist visits, Munce and colleagues (2009) found that Canadians with SCI were most likely to be high users of specialist services if they were younger and if they lived in chronic care. Both Bockeneck (1997) and van Loo and associates (2009) found that patients preferred specialist care, and were most happy to receive their follow-up care from rehabilitation specialists rather than community care.

Donnelly and colleagues (2007) show that people with long-term spinal cord injuries develop complex rubrics for navigating their personal health care systems. There is considerable confusion about which issues are most appropriate to bring to the family physician versus the physiatrist, and there are significant international differences in who does what. Beatty and colleagues (2003) surveyed adults with a variety of disabilities in the US, and found that about 63% of those with SCI indicated a need for primary care, while 33% reported an unmet need for primary care (meaning a self-report of service needed but not received). A troubling finding of the same study was that unmet needs were greatest among those with the poorest health and lowest incomes. van Loo et al. (2009) reported that 72% of their sample reported unmet needs, particularly related to rehabilitation consultation, telephone consults and home visits.

The most prevalent impediment to accessible primary care is the need for specialized expertise. In Australia, Cox and associates (2001) found that 81% of people living in the community with SCI reported limited local provider expertise, and 25% indicated a high need for specialist outreach services. Goetz and colleagues (2005) showed that clinical guidelines for specialized primary care can improve outcomes for people with SCI, but adherence to guidelines does not necessarily follow publication. Implementation strategies, such as improved documentation forms and procedural flowsheets, significantly increased adherence and promoted improved care.

Donnelly and colleagues (2007) noted that physical accessibility of the office and equipment could be an issue in primary care. These results came from surveys of people with long-standing spinal cord injuries in the US, Canada and Great Britain. Munce and associates (2009) noted that geography might be an impediment to access, since emergency room visits were twice as common for those living in rural areas. Often in rural areas, family physicians provide the medical service in emergency rooms after hours, and the central location of the emergency department in a rural community may provide easier access for patients. Cox and colleagues (2001) found that home visits and telephone consultations were preferred methods for increasing accessibility to primary care.

According to Donnelly and colleagues (2007) satisfaction was high (~75%) with quality and accessibility of care for both family physicians and rehabilitation specialists. One program where satisfaction was particularly high was the annual Comprehensive Preventive Health Evaluation (CPHE; Colllins 2005). In a large sample of American veterans with SCI, compliance with CPHE was related to having health needs and issues successfully addressed. van Loo and colleagues (2009) found that 23% of visits to family physicians in their sample were to obtain annual follow-up.

Guilcher and associates (2010) add to information about primary care utilization in Canada, showing that in the first year following discharge from rehabilitation, people with non-traumatic SCI made statistically more visits to the family physician than those with traumatic SCI. There was, however, no difference in use of emergency departments between traumatic and non-traumatic injuries. Highest primary care utilization was related to older age, living in an urban area, and greater functional limitation. This study is consistent with findings by Munce and colleagues (2009) that higher emergency room utilization was related to living in a rural area.

DiPonio and colleagues (2011) confirmed earlier findings that limited provider knowledge about SCI was a significant barrier to access. In a survey of emergency room medical residents, they found knowledge generally poor (47%) for six potentially life-threatening situations that might bring someone with a spinal cord injury to the emergency department.

One article evaluated access to dental services (Yuen et al. 2010). These authors showed that people with SCI use dental care at the same rate as the general population. The greatest impediments to access were physical barriers and cost, especially for those without insurance.

In this most recent update, two articles were added to access and care, with Hagen and colleagues (2012) finding that individuals with complete injuries were more satisfied with their GP than those with incomplete injuries. Guilcher et al. (2013) found that approximately 50% of emergency department visits among those with SCI were either ‘potentially preventable’ or ‘low acuity’, suggesting that there is considerable over reliance of the ED among this population.

Conclusions

There is level 4 evidence that individuals with tSCI are using the ED for conditions that could be managed in primary care approximately half of the time (Guilcher et al. 2013)

There is level 4 evidence that GP utilization is related to older age, functional disability, and complications (Munce et al. 2009; Guilcher et al. 2010)

There is level 4 evidence that individuals living in rural areas are more likely to visit the Emergency Department than those living in cities (Munce et al. 2009; Guilcher et al. 2010).

There is level 4 evidence that adherence to clinical guidelines improves with targeted implementation plans (Goetz et al. 2005).

There is level 5 evidence that individuals with incomplete injuries are less satisfied with their GP than those with complete injuries (Hagen et al. 2012).

There is level 5 evidence that factors predicting access to health services include health plan type, health condition, health status, severity of condition, income level and age (Beatty et al. 2003).

There is level 5 evidence that an annual Comprehensive Preventive Health Evaluation at the SCI centre is related to improved health care utilization and having health, psychosocial, and equipment needs met (Collins et al. 2005).

There is level 5 evidence that a minority of physiatrists are willing or capable of providing primary care to those with disabilities (Francisco et al. 1995).

There is level 5 evidence that there is considerable duplication between primary care and physiatry, despite high satisfaction with both (Donnelly et al. 2007).

There is level 5 evidence that there are significant differences in service utilization between Canadians, Americans, and Britons, but no difference in access to and satisfaction with the services (Donnelly et al. 2007).

There is level 5 evidence that limited knowledge of SCI, lack of funding, and service fragmentation are barriers to primary care (Cox et al. 2001; DiPonio et al. 2011)

There is level 5 evidence that people with spinal cord injuries use dental care at approximately the same rate as the general population (Yuen et al. 2011).

People with spinal cord injuries tend to be high users of primary care.

A large majority of people with spinal cord injuries have a family doctor and are satisfied with care received, but there is evidence that those with incomplete injuries are less satisfied than those with complete injuries. People with spinal cord injuries are using the emergency department for conditions that could be managed in primary care.

Lack of SCI-specific expertise appears to be the greatest impediment to access to primary care. Physical barriers are also encountered in some practices.

Unmet health needs are a significant problem for people with SCI in primary care, with information needs in particular being poorly met.

There is no consensus about the role of physiatry in primary care. Many people with SCI are content to receive their primary care from a physiatrist, but there is some question as to whether physiatrists are the appropriate primary care provider.

Coordination is needed to ensure continuity and coverage when multiple providers are involved.

3.0 Outreach Programs

A number of models have been proposed in the literature for enhancing access and quality of primary care for people with disabilities. This review found evidence only regarding outreach models where expert providers, usually from an institutional rehabilitation setting, reach out to supplement the resources of community primary care settings. Table 2 presents information on multidisciplinary outreach programs, including telehealth.

Table 2: Outreach Programs

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
Dorstyn et al. 2012 Australia Randomized Controlled Trial N=40 PEDro = 8	**Population:** Adults aged 18+ who were recently discharged from an inpatient spinal rehabilitation centre; 69% men, 59% married or in a relationship; 62% had paraplegia; 56% traumatic SCI; 64% incomplete. **Treatment:** 12-week telecounselling program which included biweekly phone consults. Aimed to be brief (average less than 20 minutes), and based on motivational interviewing technique. Standard care involved routine medical follow-up and physical therapies. **Outcome measures:** Depression Anxiety Stress Scale-21; Mini International Neuropsychiatric Interview; Spinal Cord Lesion Emotional Wellbeing and Coping Strategies Questionnaires; and the Multidimensional Measure of Social Support.	1. Telecounselling group experienced small reductions in depression (*d* = 0.32), anxiety (*d* = 0.24), and stress levels (*d* = 0.27) immediately post-intervention, but a small to moderate increase in anxiety at a 3 month follow-up (*d* = –.37) 2. The telecounselling group also experienced some small to moderate improvements in emotionally adjusting to their SCI (fewer intrusive thoughts *d* = -.53; greater acceptance *d* = .46) 3. Few participants (20 per group) contributed to significant pre-trial differences between groups (completeness of SCI, length of stay and discharge FIM scores) and non-statistically significant treatment effects.
Myers et al. 2012 USA Pre-post N=26	**Population:** 26 males with SCI, at high risk of CVD **Treatment:** 2 year CVD risk intervention program involving frequent telephone contact by a case manager, in person visits by a dietician, physical therapist and exercise therapist **Outcome Measures:** weight, physical activity patterns, dietary patterns, plasma insulin, homeostatic insulin resistance, total cholesterol/hdl ratio	1. Only 10 of 26 participants completed the entire 2 year program. 2. Despite this, significant improvements were demonstrated in weight, plasma insulin, insulin resistance, and total cholesterol/hdl levels.
Hoffman et al. 2011 USA Post-test evaluation N= 488	**Population:** 422 people attending the SCI Forum in person; 2510 hits on the video Forum (n=66); 42.4% of online viewers have SCI, 45.3% of live participants. **Purpose:** comparison of in-person vs. on-line SCI educational forum **Outcome Measures:** Consumer rating of forum; average hits per month, location of web visitors, ratings of videos, comments	1. No significant difference in ratings for in person vs. on-line forums 2. Higher scores for in person vs. on line for knowledge (96 vs 88%), attitude (64 vs 52%) and behavior (68 vs 61%). 3. On-line format more accessible.

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
Radomski et al. 2011 USA Pre-post evaluation N=13	**Population:** 6 male, 4 female (completed program); median age 53 years; median years post-injury 8.5; all complete injuries. **Treatment:** 12 week program called *Take Action* that includes an assessment by a nutritionist, an exercise physiologist and physical therapist to establish individualized diet and exercise program. **Outcome Measures:** Measures were conducted at baseline, 12 weeks and 24 weeks (only reported on 12 week end of program data). Body composition using skinfold thickness; body weight/BMI; resting metabolic rate using the BodyGem; peaker oxygen uptake (VO2); body composition (fat versus lean mass); readiness to change scale; general well-being scale; goal attainment scaling.	1. Significant improvements were observed on the goal attainment scaling, weight, skinfold body fat percent, waist and hip girth, grip strength, and resting systolic pressure.
Schladen et al. 2011 USA Qualitative N= 3	**Population**: 3 SCI participants with (1 F), 2 paraplegia, 1 tetraplegia **Treatment**: No treatment **Outcome Measures**: Semi-structured interviews on diet management, pressure relief, cardiometabolic disease screening and preventive care, consumer interest. Number of hits counted for SCI-focused media over Youtube	1. During the 30-day period viewing period, the 10 videos on YouTube logged 6,136 views. 2. Need for timely transfer of knowledge and information among providers; Lack of understanding of special circumstances of persons with SCI 3. Need for up-to-date evidence-based knowledge to effectively manage health. 4. Youtube has the potential to be a useful tool for exploring the interests of the SCI consumer community
Young-Hughes & Simbarti 2011 USA Post-test evaluation N=76	**Population:** 76 SCI veterans (3% F), received wound care for decubitus ulcer, cellulitis, osteomyelitis, or open wounds **Treatment:** wound care by specialty tele-consultation vs traditional care **Purpose:** Comparison of cost of telehealth vs in person wound care **Outcome Measures:** inpatient admissions, outpatient encounters, costs for care	1. Tele-consultation group had significantly more outpatient encounters (12 vs. 4, p = .007; 70 vs 52% of participants), and higher median cost per outpatient encounter ($440 vs. $141, p < .01) 2. No significant difference in inpatient admissions between groups, but tele-consultation group had longer inpatient stays (median 81 vs. 19 days, p=0.05); No significant difference in inpatient cost.
Van Til et al. 2010 The Netherlands Cross-sectional N SCI=38	**Population:** 39 SCI patients (29 male, 10 female; mean age:42 yrs **Treatment:** Self administered web-based Decision Aid (DA) for treatment options for arm-hand impairment **Outcome measures:** Demographics, knowledge score after use of DA	1. Significant reduction of decisional conflict (p<0.01); decreased feeling of uncertainty (p=0.02) and feeling uninformed (p<0.01). 2. The DA did not influence the patient's desire to participate in decision-making processes. It is suggested that although most patients want to be informed about disease, they do not necessarily want to be involved in treatment decision-making
Bloemen-Vrencken et al. 2007 The Netherlands Prospective Controlled Trial N=62	**Population:** 31 experimental subjects (24 male, 7 female); mean age: 37.8±13.8 yrs; Injury: paraplegia (n=18) or tetraplegia (n=13). 31 control subjects (24 male, 7 female); mean age: 36.1±13.6 yrs; Injury: paraplegia (n=18) or tetraplegia (n=13).	1. No significant differences seen in prevalence of pressure sores and urinary tract infections between groups. 2. No significant difference seen in re-admission rates between groups. 3. Quality of follow-up care experienced not

Author Year; Country Score Research Design Total Sample Size	**Methods**	**Outcome**
	Treatment: Transmural care (nurse as a liaison between subject, primary care and rehabilitation centre) for at least 1 yr after discharge in addition to the usual follow-up care; Control group: received usual follow-up including periodic outpatient visits to rehabilitation center. **Outcome measures:** Prevalence of pressure sores and urinary tract infections during first year after discharge; number and duration of re-admissions to hospital and rehabilitation centers due to pressure sores, bladder and bowel problems in the first year after discharge.	significantly different between groups.
Williams 2005 UK Case-series N=31	**Population:** 31 subjects seen at experimental nurse-led clinic on 6 different days **Treatment:** Nurse-led clinic: holistic nursing assessment, peer-support group, **Outcome measures:** Effectiveness of nurse-led services	1. Reported benefits from nurses' up-to-date knowledge of specific bowel/bladder problem-solving approaches. 2. Patients perceived nurses to be more understanding, better informed and found sessions more informative, practical and helpful.
Prabhaka & Thakker 2004 India Post-test N=546	**Population:** 546 subjects (164 male, 382 female); **Treatment:** A home visit with outreach team consisting of: counsellor, surgeon, physiotherapist, occupational therapist, prosthetist and orthotist engineer, medical social worker and a nurse. Complete assessment of rehabilitation performed including vocational, bladder-bowel, and sexual rehabilitation. Researched problems faced by SCI patients, family and societal relations, available support and opportunities for vocational rehabilitation. **Outcome measures:** Evaluation and improvement of rehabilitation to decrease the rate of hospital re-admissions.	1. Home visit program decreased the number of re-admissions, improved status of rehabilitation and raised quality of care for patients.
Beck & Scroggins 2001 USA Pre-post N=19	**Population:** Persons with tetraplegia (n=3) and long-term health care providers (n=16). **Treatment:** Health Maintenance Education Program made up of 3 phases: 1. 1-day interdisciplinary workshop to provide research-based knowledge on care; 2. Collaborative home visit to provide individualized assessment, education and intervention; 3. 12-months of on-going support to the consumer and care provider relationship. **Outcome measures:** Program evaluation forms.	1. Statistically significant increase in knowledge of: prevention of respiratory complications ($p<0.05$); prevention & treatment of autonomic dysreflexia ($p<0.05$); prevention of spasticity ($p<0.01$); reportable symptoms ($p<0.01$); effects of aging ($p<0.001$); availability of community resources ($p<0.01$). 2. Benefits included: demonstration of skills, on-site evaluation, awareness of resources 3. Suggested modifications: educational content regarding client vulnerability, client advocacy, discussion of role of agencies.

Table 3: Systematic Review of Tele-Health

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
Dorstyn et al. 2013 Australia AMSTAR = 5 N=272	**Population:** 7 independent studies published between 2001-2011, all included those with SCI **Purpose:** Systematic review of telecounselling interventions in spinal cord injury **Outcome measures:** Varied, included health and psychological well-being, provision of information, peer-support.	1. Some evidence that telecounselling can significantly improve management of common comorbidities, including sleep difficulties and pain. 2. Some gains in quality of life at 12 months after treatment.
Dorstyn et al 2011 Australia AMSTAR = 7 Meta-analysis N = 204	**Population:** 8 studies published between 1970-2010, 3 involving SCI **Purpose:** meta-analysis of telehealth psychological interventions for people with SCI & other disabilities **Outcome Measures:** 22 standardized outcome measures, incl. QOL, depression, coping, social support, community integration, impairment	1. Strong evidence that coping, community integration and health-related quality of life associated with telehealth counselling 2. Improvements attributed to attention and early intervention on new health issues and complications

Discussion

The highest quality evidence found in this review showed no effect of an outreach program for maintaining health after discharge from rehabilitation (Bloemen-Vrencken et al. 2007). Bloemen-Vrencken and associates (2007) saw no difference in complications, readmissions, or quality of primary care when a nurse provided liaison from rehabilitation to community primary care.

Another approach to outreach involved a nurse-led clinic aimed at enhancing bowel and bladder care. Participants reported more up-to-date and practical information was obtained from nurses than from their usual primary care providers (Williams 2005).

Beck and Scroggins (2001) also describe an educational intervention aimed at people with tetraplegia and their caregivers. They found significant increases in knowledge and skills related to respiratory complications, autonomic dysreflexia, spasticity, reportable symptoms, effects of aging and availability of community resources.

Other strategies for improving primary care to people with spinal cord injuries include the use of home visits. Prabhaka and Thakker (2004) showed a decrease in readmissions, and an increase in functional status and quality of care using a home visit program.

Since 2011, there have been three articles assessing telehealth programs and three discussing web-based outreach programs. These interventions were typically compared with the more resource-intensive in-person approach to outreach. Dorstyn and associates (2011) compare three published approaches to telehealth technology and applications. Based on meta-analysis, they conclude that there is strong evidence that telephone-based outreach is effective. Young-Hughes and colleagues (2011) however found that for severe problems with significant functional implications, such as pressure ulcers, the in-person option was more effective. A recent study comparing a telephone outreach program to standard care found that the treatment group experienced small reductions in depression, anxiety, and stress levels immediately post-intervention, but a small to moderate increase in anxiety at a 3 month follow-up (Dorstyn et al. 2012). The telecounselling group also experienced some small to moderate improvements in emotionally adjusting to their SCI. These results suggest that telehealth shows promise but further trials incorporating longer treatment periods and larger numbers of participants are needed to definitely establish treatment effects, as well as to eliminate any pre-trial group differences.

Radomski et al. (2011) found that a 12-week weight management program helped individuals with SCI reach their weight and body measurement goals, and Myers et al. (2012) found that an intensive program involving a case manager, dietician, physician and exercise therapists resulted in improvements in some CVD risk factors though both of these studies had small numbers of participants.

Three articles described web-based information programs on general SCI issues (Hoffman et al. 2011), specific skills (Schladen et al. 2011) and treatment decisions (van Til et al. 2010). For those patients who are comfortable with internet technology, these innovative options appear to hold considerable promise.

Conclusions

There is level 1a evidence from meta-analysis that telehealth outreach is effective for meeting information needs of patients (Dorstyn et al. 2011)

There is level 1a evidence from systematic review that telecounselling is effective for managing common SCI comorbidities, including sleep difficulties and pain (Dorstyn et al. 2013)

There is level 1a evidence that telephone counselling led to improvements in anxiety, depression and coping following SCI but more powerful research is required to establish statistically significant differences (Dorstyn et al. 2012).

There is level 2 evidence that an outreach program (Transmural care - nurse liaison from rehab to primary care) does not appear to be effective in reducing pressure sores, urinary tract infections or hospital re-admission rates (Bloemen-Vrencken et al. 2007)

There is level 4 evidence that a weight management program can help individuals meet their goals for weight and body measurements (Radomski et al. 2011).

There is level 4 evidence that outreach in the form of home visits from a multidisciplinary team from the rehab centre led to fewer re-admissions and improved rehab outcomes (Prabhaka et al. 2004).

There is level 4 evidence that a multidisciplinary Health Maintenance Education outreach program improves patient satisfaction with primary care and increases knowledge of respiratory complications, autonomic hyperreflexia, spasticity, aging and community resources (Beck and Scroggins 2001).

There is level 4 evidence that a specialised nurse-led community clinic provided up-to-date and readily applicable knowledge about bowel and bladder issues and skin breakdown, and was preferred over a medical clinic (Williams 2005).

There is level 4 evidence suggesting an online forum is not as effective as in-person education, despite being more accessible (Hoffman et al. 2011).

There is level 5 evidence that an intensive dietary and exercise program can improve markers of CVD risk (Myers et al. 2012).

There is level 5 evidence that teleconsultation for wound care led to more outpatient encounters and higher median cost than traditional care (Young-Hughes and Simbarti 2011).

There is level 5 evidence that a web-based Decision Aid for arm-hand treatment options reduces decisional conflict and feelings of uncertainty (van Til et al. 2010).

There is mixed evidence for the effectiveness of outreach programs for maintaining health in the community with SCI.

4.0 Health Issues of Key Importance in Primary Care for SCI

The final section of this review presents articles discussing the most common health concerns experienced by people with SCI in the community, and those issues most typically seen in primary care. This section is made up of 13 surveys of patients and providers, aiming to increase awareness of the nature and scope of health concerns typically experienced by people living in the community with spinal cord injuries. Table 4 summarizes the health issues and information needs of individuals with SCI when they seek primary care.

Table 4: Health Issues of Key Importance

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
Evans et al. 2011 USA Cross-sectional Survey N= 118	**Population:** 118 VA clinicians; 80 physicians, 20 nurse practitioners, 18 physician assistants **Purpose:** To assess provider knowledge of infection control in SCI **Treatment:** No treatment **Outcome Measures:** internet based survey of antimicrobial prescribing and infections resistant to antimicrobials	1. 77.1% aware antibiotic prescribing increased drug resistant infection 2. 61.0% agreed patient demand a major reason for over-prescribing antibiotics; 3. 17.8% admit they over-prescribe antibiotics 4. 75% agree with active surveillance for antibiotic resistant organisms; 5. 67.8% believed that reducing the use of a particular drug could reduce antibiotic resistance
Fann et al. 2011 USA Cross-sectional Survey N=947	**Population:** 947 participants with SCI; mean age 43.8, YPI 11.0. **Purpose:** Survey of depression and co-morbid psychological conditions **Treatment:** No Treatment **Outcome Measures:** Patient Health Questionnaire-9 (PHQ-9), Depression Scale, psychiatric history questionnaire, Cornell Service Index, current medication use	1. Prevalence of major depression endorsed by 23%; suicidal ideation endorsed by 15%; high lifetime prevalence of psychiatric disorders, especially anxiety (60% among currently depressed, 28% among non-depressed) 2. 22% of depressed participants currently receiving treatment 3. Only 11% of depressed participants receiving guideline-level therapy
Findley et al. 2011 USA Retrospective Cohort N=8,334	**Population:** 98% male; 54.7% paraplegia; 46% had veterans association healthcare; over a 3 year period 62% had no mental illness. **Treatment:** No treatment. **Purpose:** Use administrative data to evaluate mortality among individuals with SCI comparing those with mental health	1. After adjusting for independent variables, HR of death for psychosis was 1.47 (95% CI, 1.24-1.75) for alcohol and drug use was 1.30 (95% CI, 1.11-1.53)

Author Year; Country **Score** **Research Design** **Total Sample Size**	**Methods**	**Outcome**
	issues to those without. **Outcome measures:** Mental health disorders (ICD-9); substance use disorders (ICD-9-CM); constructed variable 1.) MI only; 2.) alcohol and /or drug use and tobacco; 3.) both MI and/or drug use; and 4.) neither MI nor alcohol or drug use	
Thietje et al. 2011 Germany Prospective cohort study N = 214	**Population:** 214 patients admitted to trauma hospital **Purpose:** To investigate knowledge acquisition about pressure ulcers and bladder management before, during and after admission and discharge **Treatment:** no treatment **Outcome measures:** SCIM II score (functional ability) and Knowledge Boberg score	1. Only 47% of participants had good knowledge of bladder or skin complications at discharge. 2. Age was negatively associated with knowledge and knowledge acquisition. 3. After discharge, the general practitioner and the physiotherapist became the most important SCI information resources.
Weaver et al. 2011; USA Observational study N=1210	**Population:** 1210 SCI/D respondents (4% F), 61% incomplete injury; 37% tetraplegia; mean age: 60.3; mean years YPI: 20.7 **Purpose:** Survey of smoking behavior among SCI veterans **Treatment:** no treatment **Outcome measures:** Survey, medical records, smoking behavior and attitudes, readiness to quit, key informant interviews	1. 22% were current smokers, 51% were past smokers and 27% never smoked 2. Current smokers significantly more likely to have obesity, alcohol problems, COPD, asthma, shortness of breath, chronic cough, chest wheeze, depression (P<.01) 3. 70% of current smokers reported more pain than the past smokers (p<.01). 4. Smoking cessation strategies need to be encouraged by health care providers.
Evans et al. 2010 USA Retrospective Cohort N= 1277	**Population:** 1277 veterans with SCI with acute respiratory infection (ARI); 57.1% paraplegia, 64.3% incomplete injury, mean age 59.1, mean YPI 20.3 yrs **Purpose:** follow-up survey of 2006 study of SCI outpatients **Treatment**: new antibiotic prescription within 3 days of ARI **Outcome Measures:** Survey on long term outcome of traumatic SCI, health-care utilization, subsequent outpatient visit or hospitalization	1. 53.2% of patients with ARI were prescribed an antibiotic. 2. 47.0% had subsequent outpatient visit within 30 days 3. No significant difference in health care utilization for those prescribed antibiotic 4. In light of potential for antibiotic resistance, curbing antibiotic prescription does not have deleterious impact on outcomes in patients without chronic respiratory condition
Norman et al. 2010; Canada Qualitative N = 12	**Population:** 12 patients (58% F), mean age 52, mean YPI 16.9 **Purpose:** to explore information needs regarding chronic pain **Treatment:** no treatment. **Outcome measures:** Qualitative interviews; Brief Pain Inventory (BPI-SF), Short Form McGill Pain Questionnaire (MPQ-SF)	1. Majority of participants not satisfied with information received from family physician. 2. Two themes warrant further research: 'nobody knows' - physicians, nurses, family, friends don't understand chronic pain experience; 'desire to educate others' about SCI-related chronic pain.
Ashe et al. 2009 Canada Observational (Survey) N=22	**Population:** 22 physiatrists treating SCI patients. **Treatment:** No treatment. **Purpose**: To assess opinions about bone health and treatments among physiatrists **Outcome measures:** A survey assessing	1. 86% of physiatrists considered bone health after SCI is an important issue. 2. Most physiatrists reported that pharmacological treatments were most beneficial, whereas rehabilitation modalities had lower support for effectiveness.

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
	opinions and practice patterns relating to: bone health management, assessment of bone health management, and treatment of bone health after SCI.	
Ashe et al. 2009 Canada Observational (Survey) N=22	**Population:** 22 physiatrists treating SCI patients. **Treatment:** No treatment. **Purpose**: To assess opinions about bone health and treatments among physiatrists **Outcome measures:** A survey assessing opinions and practice patterns relating to: bone health management, assessment of bone health management, and treatment of bone health after SCI.	1. 86% of physiatrists considered bone health after SCI is an important issue. 2. Most physiatrists reported that pharmacological treatments were most beneficial, whereas rehabilitation modalities had lower support for effectiveness.
van Loo et al. 2009 Netherlands Observational (Survey) N = 453	**Population:** Mean age = 47.7; Male = 65.1%; Complete tetraplegia = 19.9%, Incomplete tetraplegia = 14.4%, Complete paraplegia = 46.3%, Incomplete paraplegia = 19.4% **Treatment:** No treatment. **Purpose of the study:** To determine the care received for secondary condition and extra care needs, and to determine if the secondary conditions were preventable. **Outcome measures:** Questionnaire inquiring about frequency of SCI-related contacts with professional caregivers during previous 12 months, secondary conditions and which conditions were perceived as most important, what kind of care they received, and how the condition could have been prevented.	1. 58% of contacts with family physician were related to secondary complications, 34% of which were preventable. 2. On average, participants mentioned 8 secondary conditions, and 3.9 most important secondary conditions, including: bladder and bowel regulation; pain; spasms, and sexuality and pressure sores. 3. 50% of the pressures sores, 25% of the bladder, bowel and sexuality problems could have been prevented according to the participants. 4. 72% indicated need for additional care due to secondary conditions. 5. For most important secondary conditions, 47% received care, and extra care in 41.3%.
Donnelly et al. 2007 Canada, US, & UK Observational (Survey) N=373	**Population:** 373 individuals with SCI (315 male, 56 female); 127 Canadian [aged 55.9 (±10.7) years; 32.1(±8.4) years of SCI]; 162 British [aged 62 (±7.7) years; 39.2 (±5.5) years of SCI]; 84 Americans [aged 56.7(±8.9) years; 35.3 (±6.5) years of SCI] **Treatment:** No treatment. **Purpose:** 1) To describe utilization, accessibility and satisfaction with primary and preventative health care services by individuals with long term SCI, 2) To compare results across three countries; Canada, US, and UK. **Outcome measures:** 46-item measure [compilation of Health Care Questionnaire (HCQ) and Patient Satisfaction with Health Care Provider Scale (PSHCPS)]surveying utilization, access and satisfaction with primary and preventative health care services	1. Issues of sexual health, alcohol use, community functioning, and emotional health were not addressed by either FD or SIS for > 70% of participants. 2. The highest utilization of FD was for pain (86%, p<0.05) and fatigue (84%, p<0.05); The highest Utilization of SIS was for routine rehab follow-up (91%, p<0.05)
Gontkovsky et al. 2007 USA Observational (Survey)	**Population:** Chronic SCI, community dwelling, 1-13 years post injury, mean age 42±14 years	1. Information needs most endorsed were: Aging (73%), SCI Research Information (66%) and SCI Educational Information

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
N=82	**Treatment:** No treatment. **Purpose**: To examine the perceived information needs of individuals with chronic SCI and determine the factors that influence these needs **Outcome measures:** A questionnaire assessing issues of access to health and healthcare information needs (23 domains) since inpatient discharge.	(63%) 2. ≥16% of the sample reported information needs in all 23 domains. 3. Six domains were endorsed by at least half of the subjects, and 15 domains were endorsed by at least one-third of the sample. 4. Ethnic minority participants endorsed significantly more information needs.
Collins et al. 2005 USA Observational (Survey) N=853	**Population:** 853 veterans with SCI **Treatment:** No treatment. **Purpose:** to assess patient satisfaction with the annual comprehensive preventative health evaluation (CPHE) **Outcome measures:** 21 item questionnaire about the satisfaction with CPHE content, whether needs were met, what respondents valued about the examination and health concerns they would like to see addressed. Answers were dichotomized for analysis purposes.	1. 76% of survey respondents had completed the CPHE within the previous year. 2. Top two reasons for completing the CPHE was to get medication and supplies refilled and talking to doctors. 3. Topics discussed during the CPHE were muscle strength and weakness, bladder care, chronic pain, digestion and bowel care issues, and equipment problems. 4. Completion of CPHE was related to other health care utilization and having health needs met.
McDermott et al. 2005 USA Case-control N=3636 (1552 with disability, 35 SCI)	**Population:** 35 SCI (8 female, 12 with paraplegia, 23 with tetraplegia) **Treatment:** No treatment. **Purpose:** Computerized medical records from 1990 to 2003 and companion paper records were reviewed. **Outcome measures:** Determine the rate of depression among individuals with disabilities, comparing both within the disability group (eg different diagnosis) and to the control group.	1. Patients with disabilities have significantly higher rates of depression (p=0.019) 2. 28.6% of people with SCI were found to be depressed. 3. Patients with trauma (SCI and TBI) had significantly earlier onset of depression compared to controls (p=0.0007) 4. By age 50, 16-17% of patients with trauma had depression. 5. By age 60, 45% of patients with trauma had depression compared to 18% of controls.
Beatty et al. 2003 USA Observational (Survey) N=800 (169 SCI)	**Population:** 800 adults (≥18 years; 69% female) with either arthritis (357), SCI(169), MS(164), or CP (110) **Treatment:** No treatment. **Purpose:** To survey patterns of need for and access to specific health care services by persons with disabilities or chronic conditions and the relationship between access and factors identified as predictors of access. **Outcome measures:** 80 item self-report questionnaire inquiring about perceived need for, and access to five specific health care services [primary care physician (PCP); specialist care (SC); physical rehabilitation (PR); assistive equipment (AE); and prescription medications(PM)] & health plan type [fee for service (FFS); or managed care organization (MCO)]	1. Overall need for health services varied; 62.7% reported a need for PCP, 57.4% for SC, 39.1% for PR, 69.2% for AE, & 94.1% for PM 2. Need Vs. actual receipt of services: Only 67% of needed PCP was received; 75.3% of SC; 40.9% of PR; 69.2% of AE; and 93.1% of PM.
Vaidyanathan et al. 2001 UK Observational (Survey)	**Population:** SCI patients attending a follow up clinic in a Regional Spinal Injuries Centre. **Treatment:** No treatment.	1. 106 (83%) patients wished to receive written information 2. 115 (90%) preferred to receive a copy of their MRI with interpretation and felt it would

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
N=128	**Purpose:** To collect information on desire to receive written information about changes in their condition and whether this information would cause needless anxiety to patients and or their relatives/carers. **Outcome measures:** 28 item yes/no survey.	be valuable to show their GP. 3. 122 (95%) did not feel that written information would cause needless anxiety 4. 109 (93%) wished to receive written information about changes in their medical condition after readmission to the spinal unit.
Oshima et al. 1998 USA Observational (Survey) N=44	**Population:** 30 Internal Medicine (IM) students (2nd (57%) and 3rd (43%) year of residency training) and 14 Ob/Gyn students (2nd(14%),3rd (43%)and 4th (43%) year). **Treatment:** No treatment **Purpose:** To assess knowledge base and comfort level of potential physicians when treating women with SCI. **Outcome measures:** A hypothetical case scenario of a pregnant woman with tetraplegia was presented. Students were asked how they would conduct an examination, deal with her spasticity and how they would assist her to the exam table. They were also asked to record their comfort level in managing the patient.	1. 75% of IM residents and 67% of Ob/Gyn indicated that they would conduct a pelvic examination. 2. 53% of IM and 64% of Ob/Gyn said they would use staff to lift her on the table. 40% of IM said they did not have resources/knowledge, 21% of Ob/Gyn reported access to an electric table. 3. 17% of IM and 14% of Ob/Gyn said they did not know how to manage spasticity. 4. 36% of Ob/Gyn students expressed concern about spasticity as a complication 5. 30% of IM students said they would consult obstetrics and 36% of Ob/Gyn said they would refer her to 'high risk' obstetrics; 43% would also refer her to physiatry. 6. Most Ob/Gyn students reported their comfort level as neutral for this case while IM students reported as uncomfortable.
Glickman et al. 1996 England Observational (Survey) N=139	**Population:** 139 General Practitioners (GPs) with SCI patients **Treatment:** No treatment. **Purpose:** to examine the workload and common problems facing primary care teams in SCI management. **Outcome measures:** Mailed survey inquiring about annual number of consultations with the patient regarding gastrointestinal, urological and dermatological problems, and the magnitude of pain and spasticity	1. 78.5% of the patients had multiple problems; 11.5% had 0 problems, 10.1% had 1 problem. 2. 72% had urological problems; 49.6% had colonic issues; 41.7% had dermatological problems; 65.5% had spasticity; and 55.4% had pain. 3. 53.9% of the GPs offered services to change urethral catheters; 15.8% were able to change suprapubic catheters; and 29.5% offered psychological or social counselling.
Warms 1987 USA Observational (Survey) N=59	**Population:** 59 adult (53 males; 5 females) patients with SCI, at least two years post-injury. Age range 21-60. 29 cervical injury; 24 thoracic injury; 6 lumbar or sacral injury. **Treatment:** No treatment. **Purpose:** To survey the source and content of health care received by individuals with spinal cord injury and to describe what healthcare services are desired. **Outcome measures:** A self-reported survey assessing: source of health care, content of care, and healthcare services desired, but not obtained.	1. 52.9% reported discussing bladder or kidney problems, 47.1% reported discussing pressure sore prevention, and 23% reported discussing spasticity, and 23% discussed bowel issues. 2. 80% of issues raised were disability-related. 3. Unmet needs for health promotion services, fitness and diet counselling.

Discussion

There is consensus in the literature about the issues that are of most concern to people with spinal cord injuries when they seek primary care. Fifty-eight percent (58%) of contacts with the family physician were related to secondary complications (van Loo et al. 2009). Most consistently mentioned were bowel and bladder problems and pain (Donnelly et al. 2007; Collins et al. 2005; Glickman et al. 1996; Warms 1987; Williams 2005). Eighty percent (80%) of SCI patients in primary care bring multiple problems to their family physician (Glickman et al. 1996), and according to Warms (1987), 80% of the issues raised are disability-related.

Both Collins et al. (2005) and Beatty et al. (2003) refer to the need for adaptive equipment and prescription medications as concerns in primary care. Collins et al. (2005) notes that these are key reasons why individuals seek an annual check-up. Beatty et al. (2003) notes that 94% of patients with SCI have needs for prescription medications, and 69% for adaptive equipment. In both instances, the primary care physician is the coordinator for these needs. They also found that 93% of prescription medication needs and 69% of equipment needs were met.

Ashe and associates (2009) provide support for the importance of bone density, and the need for pharmacological treatment if indicated. Two articles highlighted the need for attention to skin care and spasticity. Glickman and associates (1996) claim that 42% of patients have dermatological issues and 65% need help with the management of spasticity. van Loo's sample in the Netherlands (2009) demonstrated that 34% of all secondary complications were preventable, especially skin complications, which were judged to be 53% preventable.

Unfortunately, there are a number of issues where unmet needs have been observed in primary care. Donnelly and colleagues (2007) noted that issues of psychological health, sexual and reproductive health, lifestyle and community not be well covered by primary care, whether it came from a family physician or physiatrist. McDermott and colleagues (2005) noted that depression is significantly higher among people with disabilities, and that it has a significantly earlier onset when the disability is of a traumatic origin. Warms (1987) also found unmet needs for health promotion and lifestyle issues.

One frequently overlooked area of primary care for people with spinal cord injuries is the area of sexual and reproductive health. Oshima and colleagues (1998) note that physicians are typically not prepared for the special issues associated with the gynaecological or obstetric needs of women with spinal cord injuries, or of the procedures necessary to provide them with a reasonable standard of primary care.

Several studies referred to the information needs of people with spinal cord injuries in primary care. Vaidyanathan and colleagues (2001) found unequivocally that patients wanted clear information about their health, preferably in written form. They wanted information shared among health providers as well as with themselves. Gontkovsky and colleagues (2007) also identified information needs in a spinal cord injured population, especially information about aging, current research and other educational offerings. Ethnic minorities in particular had a difficult time having their information needs met.

Fann and colleagues (2011) substantiated previous findings about high prevalence of psychiatric conditions among people with SCI, and found that only a small percentage (11%) were given treatment consistent with clinical guidelines. The importance of treatment for psychiatric conditions is highlighted by Findley et al. (2011) who found that mental illness and substance abuse disorders are associated with excess mortality.

Information needs continued to be an issue for people with SCI. Norman and associates (2010) found that participants depended on family physicians as an important source of information on the management of chronic pain, and were frequently unsatisfied, and felt “alone with their pain”. Family physicians were an important source of health information post discharge according to a cohort of individuals followed by Thietje and colleagues (2011). Only 47% of this cohort, however, had good knowledge about skin and bladder care at discharge from rehabilitation, and the level of knowledge did not improve up to 2½ years post-discharge. Those particularly at risk due to poor information were those over 65 years of age, and those with lower education. Weaver and associates (2011) looked at smoking and found 22% of their sample were currently smokers. Smoking was shown to exacerbate a number of important health conditions among people with SCI, including chronic pain, respiratory conditions and depression. Family physicians were seen as an important source of information about health risks and smoking cessation strategies.

Two articles by the same group of authors examined prescription of antibiotics for acute respiratory infections among people with SCI. The first study (Evans et al., 2010) showed that in uncomplicated acute cases, antibiotic use did not change subsequent health service utilization (ED visits or hospital admissions) following a visit with an acute respiratory infection. The second study (Evans et al., 2011) offered the perspective of family physicians, the majority of whom recognized the risks of over-prescribing antibiotics and were in favour of surveillance strategies and efforts to reduce the use of antibiotics.

Conclusions

There is level 2 evidence that patient knowledge of two key health risks (skin and bladder management) is poor at the point of discharge from rehabilitation (Thietje et al. 2011).

There is level 3 evidence that depression rates are higher and onset is earlier among individuals with disabilities, especially traumatic-onset disabilities, such as SCI, compared to controls (McDermott et al. 2005).

There is level 4 evidence that antibiotic prescription does not significantly affect subsequent health service use among acute uncomplicated cases of respiratory infection (Evans et al. 2010).

There is Level 5 evidence that veterans with mental illness and substance abuse issues are at increased risk of mortality (Findley et al. 2011).

There is level 5 evidence that relatively few confirmed cases of depression are receiving guideline-level treatment (Fann et al. 2011).

There is Level 5 evidence that physicians are aware that antibiotic prescription must be carefully monitored to avoid antibiotic resistance (Evans et al. 2011).

There is level 5 evidence that 80% of issues raised by patients with SCI in primary care are disability-related (Warms 1987).

There is level 5 evidence that 52% of contact with GPs was regarding secondary complications; 34% of secondary complications are believed to be preventable; 72% of people with SCI report an unmet need for health care related to secondary health conditions (van Loo et al. 2009).

There is level 5 evidence that physiatrists consider bone health after SCI as an important issue and that they favour pharmacological treatment (Ashe et al. 2009).

There is level 5 evidence that the majority of medical residents are not comfortable treating a woman with tetraplegia who has recently become pregnant (Oshima et al. 1998).

There is level 5 evidence that individuals with chronic SCI would like more information regarding SCI and health risks. Needs for lifestyle and emotional issues often go unmet (Donnelly et al. 2007).

There is level 5 evidence that health promotion and counselling needs, including smoking cessation, are typically unmet (Warms 1987; Weaver et al. 2011).

There is level 5 evidence that information about chronic pain and pain management strategies is insufficient (Norman et al. 2010).

There is level 5 evidence that ethnic minorities had the greatest unmet needs for information (Gontkovsky et al. 2007).

There is level 5 evidence that individuals with chronic SCI would like more information regarding aging with SCI, SCI research, and SCI educational information; ethnic minorities had the greatest unmet needs for information (Gontkovsky et al. 2007).

There is level 5 evidence that 90% of individuals with SCI would like to receive written information about their condition following a medical checkup (Vaidyanathan et al. 2001).

Individuals with spinal cord injury consistently raise common health issues in primary care. The most commonly raised issues are bowel, bladder and pain. Also of significant concern are skin care, equipment, medication needs, depression and bone density.

The majority of the issues raised in primary care are disability-related – specifically, they are secondary complications of the spinal cord injury.

Unmet needs in primary care pertain primarily to information needs, psychological issues, sexual and reproductive health, health promotion and lifestyle.

5.0 General Discussion and Implications

This scoping review set out to discover the current state of knowledge in the research literature about primary care for people with spinal cord injuries. Primary care is increasingly becoming an important issue for the long term health of people with SCI. Twenty articles were found in the initial review covering 29 years, and an additional 24 were found over the past two revisions. Of these, two resulted in level 1 evidence (Dorstyn et al. 2013; Dorstyn et al. 2012), 3 resulted in Level 2 evidence; that is, generalizable findings based on quasi-experimental research (Bloemen-Vrencken et al. 2007; Dorstyn et al. 2011; Thietje et al. 2011). One offered Level 3 evidence (McDermott et al 2005), and the remainder offered Level 4 or 5 evidence.

It is encouraging to note most people with SCIs report that they do have primary care coverage, either from their family physician or from a spinal cord injury specialist, and most are satisfied with the care they receive (Bockeneck 1997; Collins et al. 2005; Donnelly et al. 2007). That said, recent evidence suggests that individuals with incomplete injuries are less satisfied than those with complete injuries (Hagen et al. 2012). There appears to be some agreement that an annual follow-up visit, whether with the family physician or the rehabilitation specialist, is compatible with having one's concerns addressed and having a plan for health maintenance and prevention of secondary complications. However, significant unmet needs persist – needs for information and specialized expertise regarding spinal cord injury, (Beatty et al. 2003; Donnelly et al. 2007; Gontovsky et al. 2007; Munce et al. 2009; van Loo et al. 2009). These unmet needs are most likely a product of the complexity of lifelong spinal cord injury, and the difficulties family physicians experience remaining current with the advances in primary care for people with spinal cord injuries. There is an ongoing need for innovative methods of knowledge translation to assist family physicians with this expanding knowledge base.

Patients with spinal cord injuries are among the small percentage in any typical caseload who have multiple, complex health needs. According to Wallace and Seidman (2006) and Rosen (2006), 5-6% of the patients in a standard family practice consume about 1/3 of the practice's resources. These patients require the services of a multi-disciplinary team to adequately manage their array of health and social concerns; people with spinal cord injuries are undoubtedly in this category. They are high users of primary care and bring with them multiple needs and expectations (McColl and Shortt 2001). Despite the best of intentions, these needs may not all be met in the standard 10-20 minute family physician interaction, where there are often restrictions on the number of issues that may be raised. For patients who routinely attend with 5 or 6 issues, of which only 2 or 3 can be raised, it is little wonder that unmet needs persist, regardless of the quality of care that is delivered in that standard brief interaction.

The answer to this dilemma is not to simply ask more of family physicians, but rather to suggest alternative models of primary care for these subsets of the population with extraordinary needs. Bloemen-Vrencken et al. (2005) and McColl et al. (2009) provide review articles on models of community care for people with spinal cord injuries. Numerous authors in this review describe models such as tele-consultation, outreach, and home visiting. There is emerging evidence around teleconsultations as a model of care, with the most recent review finding improvements in sleep difficulties, pain, and improved quality of life (Dorstyn et al. 2013). Although these models have not been definitively evaluated with adequate statistical power, several studies have produced positive results in terms of secondary complications, service utilization and well-being.

The broader health literature is unequivocal that a robust system of primary care is the best assurance available of good health outcomes for the population, and reasonable health service utilization. Historically, a subset of the population with spinal cord injuries has used specialists (particularly physiatrists) to provide their primary care. This approach ensures a high degree of expertise in spinal cord injury, though there are a number of arguments against it. Not least among these is the clear preference by physiatrists to resist responsibility for primary care (Francisco et al. 1995). The primary care system is best positioned to provide comprehensive, multidisciplinary, holistic care for all, including people with spinal cord injuries.

6.0 Summary

There is level 1a evidence from systematic review that telecounselling is effective for managing common SCI comorbidities, including sleep difficulties and pain (Dorstyn et al. 2013).

There is level 1a evidence that telephone counselling led to improvements in anxiety, depression and coping following SCI but more powerful research is required to establish statistically significant differences (Dorstyn et al. 2012).

There is level 2 evidence that knowledge of two key health risks (skin and bladder management) is poor at the point of discharge from rehabilitation (Thietje et al. 2011)

There is level 3 evidence that depression rates are higher and onset is earlier among individuals with disabilities, especially traumatic-onset disabilities, such as SCI, compared to controls (McDermott et al. 2005).

There is level 5 evidence that relatively few confirmed cases are receiving guideline-level treatment (Fann et al. 2011).

There is level 4 evidence that individuals with tSCI are using the ED for conditions that could be managed in primary care approximately half of the time (Guilcher et al. 2013)

There is level 4 evidence that individuals living in rural areas more likely to visit the Emergency Department than those living in cities (Munce et al. 2009; Guilcher et al. 2010).

There is level 4 evidence that adherence to clinical guidelines improves with targeted implementation plans (Goetz et al, 2005).

There is level 4 evidence that a weight management program can help individuals meet their goals for weight and body measurements (Radomski et al. 2011).

There is level 4 evidence that antiobiotic prescription does not significantly affect subsequent health service use among acute uncomplicated cases of respiratory infection (Evans et al. 2010). There is Level 5 evidence that physicians are aware that antibiotic prescription must be carefully monitored to avoid antibiotic resistance (Evans et al. 2011).

There is level 4 evidence that GP utilization is related to older age, functional disability, and complications (Munce et al. 2009; Guilcher et al. 2010).

There is level 5 evidence that individuals with incomplete injuries are less satisfied with their GP than those with complete injuries (Hagen et al. 2012).

There is level 5 evidence that an intensive dietary and exercise program can improve markers of CVD risk (Myers et al. 2012).

There is level 5 evidence that factors predicting access to health services include health plan type, health condition, health status, severity of condition, income level and age (Beatty et al. 2003).

There is level 5 evidence that an annual Comprehensive Preventive Health Evaluation at the SCI centre is related to improved health care utilization and having health, psychosocial, and equipment needs met (Collins et al. 2005).

There is level 5 evidence that a minority of physiatrists are willing or capable of providing primary care to those with disabilities (Francisco et al. 1995).

There is level 5 evidence that there is considerable duplication between primary care and physiatry, despite high satisfaction with both (Donnelly et al. 2007).

There is level 5 evidence that there are significant differences in service utilization between Canadians, Americans, and Britons, but no difference in access to and satisfaction with the services (Donnelly et al. 2007).

There is level 5 evidence that limited knowledge of SCI, lack of funding, and service fragmentation are barriers to primary care (Cox et al. 2001; DiPonio et al. 2011).

There is level 5 evidence that 80% of issues raised by patients with SCI in primary care are disability-related (Warms 1987). 52% of contact with GP's was regarding secondary complications; 34% of secondary complications are believed to be preventable. 72% of people

with SCI report an unmet need for health care related to secondary health conditions (van Loo et al. 2009).

There is Level 5 evidence that veterans with mental illness and substance abuse issues are at increased risk of mortality (Findley et al. 2011).

There is level 5 evidence that physiatrists consider bone health after SCI is an important issue, and that they favour pharmacological treatment (Ashe et al. 2009).

There is level 5 evidence that the majority of medical residents are not comfortable treating a woman with tetraplegia who has recently become pregnant (Oshima et al. 1998).

There is level 5 evidence that individuals with chronic SCI would like more information regarding SCI and health risks. Needs for lifestyle and emotional issues often go unmet (Donnelly et al. 2007). Health promotion and counseling needs are typically unmet, including smoking cessation (Warms 1987; Weaver et al. 2011). Information about chronic pain and pain management strategies is insufficient (Norman et al. 2010). Ethnic minorities had the greatest unmet needs for information (Gontkovsky et al. 2007).

There is level 5 evidence that 90% of individuals with SCI would like to receive written information about their condition following a medical checkup (Vaidyanathan et al. 2001).

7.0 References

Ashe MC, Eng JJ, Krassioukov A. Physiatrists' opinions and practice patterns for bone health after SCI. Spinal Cord 2009; 47: 242-248.

Batavia AI. Of wheelchairs and managed care. Health Aff 1999; 18: 177-182.

Beatty PW, Hagglund KJ, Neri MT, Dhont KR, Clark MJ, Hilton SA. Access to health care services among people with chronic or disabling conditions: patterns and predictors. Arch Phys Med Rehabil 2003; 84: 1417-1425.

Beck LA, Scroggins LM. Optimizing health of individuals with tetraplegia. SCI Nursing 2001; 18: 181-186.

Bernardez SJ, Brown LT, Nora JT, Stevermer D. Primary care for the spinal cord injured patient. J Am Acad Physician Assist 1994; 7: 526-531.

Bloemen-Vrencken J, de Witte L, Post MW. Follow-up care for persons with spinal cord injury living in the community: a systematic review of interventions and their evaluation. Spinal Cord 2005; 43: 462-475.

Bloemen-Vrencken J, de Witte L, Post M, Pons C, van Asbeck F, van der Woude LH, van den Heuvel WJ. Comparison of two Dutch follow-up care models for spinal cord-injured patients and their impact on health problems, re-admissions and quality of care. Clin.Rehabil 2007; 21: 997-1006.

Bluestein D, Starling E, Moore P, Droesch J, Davis D, Wade W. Caring for a paraplegic patient and her family. J Fam Pract 1988; 27: 365-367, 370-1.

Bockenek WL. Primary care for persons with disabilities: A fragmented model of care for persons with spinal cord injuries. Am.J.Phys.Med.Rehabil 1997; 76(3 Suppl): S43-6.

Booth S, Kendall M. Benefits and challenges of providing transitional rehabilitation services to people with spinal cord injury from regional, rural and remote locations. Aust J Rural Health 2007; 15: 172-178.

Brooker C, Cousins MJ, Molloy AR. Neuropathic pain: A GP's guide. Modern Medicine of Australia 1999; 42: 58-68.

Collins EG, Langbein WE, Smith B, Hendricks R, Hammond M, Weaver F. Patients' perspective on the comprehensive preventive health evaluation in veterans with spinal cord injury. Spinal Cord 2005; 43: 366-374.

Cox RJ, Amsters DI, Pershouse KJ. The need for a multidisciplinary outreach service for people with spinal cord injury living in the community. Clin Rehabil 2001; 15: 600-606.

DiPonio L, Roth RS, Gater D, Kowalenko T, Engel K, Carson J, Curtin C. The Management of Patients with Chronic Spinal Cord Injury in Emergency Departments: Utilization and a Knowledge Survey of Emergency Medicine Residents. Top Spinal Cord Inj Rehabil 2011; 17: 38-45.

Donnelly C, McColl MA, Charlifue S, Glass C, O'Brien P, Savic G, Smith K. Utilization, access and satisfaction with primary care among people with spinal cord injuries: a comparison of three countries. Spinal Cord 2007; 45: 25-36.

Dorstyn DS, Mathias JL, Denson LA. Psychosocial outcomes of telephone-based counseling for adults with an acquired physical disability: A meta-analysis. Rehabil Psychol 2011; 56: 1-14.

Dorstyn D, Mathias J, Denson L, Robertson M. Effectiveness of telephone counseling in managing psychological outcomes after spinal cord injury: A preliminary study. Arch Phys Med Rehabil 2012; 93: 2100-8.

Dorstyn D, Mathias J, Denson L. Applications of telecounselling in spinal cord injury rehabilitation: A systematic review with effect sizes. Clinical Rehabilitation 2013; 27:1072-1083.

Evans CT, Li K, Burns SP, Smith B, Lee TA, Weaver FM. Antibiotic prescribing for acute respiratory infection and subsequent outpatient and hospital utilization in veterans with spinal cord injury and disorder. PM R 2010; 2: 101-9.

Evans CT, Rogers TJ, Weaver FM, Burns SP. Providers’ beliefs and behaviors regarding antibiotic prescribing and antibiotic resistance in persons with spinal cord injury or disorder. J Spinal Cord Med 2011; 34: 16-21.

Fann JR, Bombardier CH, Richards JS, Tate DG, Wilson CS, Temkin N. Depression After Spinal Cord Injury: Comorbidities, Mental Health Service Use, and Adequacy of Treatment. Arch Phys Med Rehabil 2011; 92: 352-60.

Findley PA, Banerjea R, Sambamoorthi U. Excess mortality associated with mental illness and substance use disorders among veteran clinic users with spinal cord injury. Dis and Rehabil 2011; 33:1608-1615.

Francisco GE, Chae JC, DeLisa JA. Physiatry as a primary care specialty. Am J Phys Med Rehabil 1995; 74: 186-192.

Glickman S, Dalrymple-Hay M, Phillips GF. Spinal cord injury after rehabilitation: the general practice experience. Br J Ther Rehabil 1996; 3: 168-171.

Goetz LL, Nelson AL, Guilhan M, Bosshart HT, Harrow JJ, Gerhart KD, Krasnicka B, Burns SP. Provider adherence to implementation of clinical practice guidelines for neurogenic bowel in adults with spinal cord injury. J. Spinal Cord Med 2005; 28: 394-406.

Gontkovsky ST, Russum P, Stokic DS. Perceived information needs of community-dwelling persons with chronic spinal cord injury: findings of a survey and impact of race. Disabil Rehabil 2007; 29: 1305-1312.

Groah SL, Stiens SA, Gittler MS, Kirshblum SC, McKinely WO. Spinal cord injury medicine. Preserving wellness and independence of the aging patient with spinal cord injury: a primary care approach for the rehabilitation medicine specialist. Arch Phys Med Rehabil 2002; 83: S82.

Guilcher SJT, Munce SEP, Couris CM, Fung K, Craven BC, Verrier M, Jaglal SB. Health care utilization in non-traumatic and traumatic spinal cord injury: a population-based study. Spinal Cord 2010; 48: 45-50.

Guilcher SJT, Craven BC, Calzavara A, McColl MA, Jaglal SB. Is the emergency department an appropriate substitute for person with traumatic spinal cord injury? Spinal Cord 2013; 51:202-208.

Hagen EM, Grimstad KE, Bovim L, Gronning M. Patients with traumatic spinal cord injuries and their satisfaction with their general practitioner. Spinal Cord 2012; 50:527-532.

Hoffman J, Salzman C, Garbaccio C, Burns SP, Crane D, Bombardier C. Use of on-demand video to provide patient education on spinal cord injury. Journal of Spinal Cord Medicine 2011; 34: 404-409.

Holcomb LO. Community reintegration and chronic spinal cord injury. SCI Nurs 2008; 17: 52-58.

Kroll T, Beatty PW, Bingham S. Primary care satisfaction among adults with physical disabilities: the role of patient-provider communication. Manag Care Q 2003; 11: 11-19.

Kroll T, Neri MT. Use of primary prevention services among male adults with cerebral palsy, multiple sclerosis, or spinal cord injury in managed care and fee-for-service. Manage Care Q 2004; 12: 6-10.

Mann L, Middleton JW, Leong G. Fitting disability into practice—focus on spinal cord injury. Aust Fam Physician 2007; 36: 1039-42.

McColl MA, Aiken A, McColl A, Sakakibara B, Smith K. Primary care of people with spinal cord injury: scoping review. Can Fam Physician 2012; 58: 1207-16.

McColl MA, Forster D, Shortt SED, Hunter DJW, Dorland J, Godwin M, Rosser W. Physician experiences providing primary care to people with disabilities. Healthcare Policy 2008; 4: 129-147.

McColl MA, Shortt S, Godwin M, Smith K, Rowe K, O’Brien P, Donnelly C. Models for integrating rehabilitation and primary care: a scoping study. Archives of Physical Medicine and Rehabilitation 2009; 90: 1523-1531.

McDermott S, Moran R, Platt T, Issac T, Wood H, Dasari S. Depression in adults with disabilities, in primary care. Disability & Rehabilitation 2005; 27: 117-123.

Middleton JW, Leong G, Mann L. Management of spinal cord injury in general practice - part 1. Aust Fam Physician 2008; 37: 229-233.

Middleton JW, Leong G, Mann L. Management of spinal cord injury in general practice - part 2. Aust Fam Physician 2008; 37: 331-338.

Munce SE, Guilcher SJ, Couris CM, Fung K, Craven BC, Verrier M, Jaglal SB. Physician utilization among adults with traumatic spinal cord injury in Ontario: a population-based study. Spinal Cord 2009; 47: 470-476.

Myers J, Gopalan R, Shahoumian T, Kiratkli J. Effects of customized risk reduction program on cardiovascular risk in males with spinal cord injury. JRRD 2012; 49: 1355-1364.

Norman C, Bender JL, Macdonald J, Dunn M, Dunne S, Siu B, Hitzig SL, Jadad AR, Hunter J. Questions that individuals with spinal cord injury have regarding their chronic pain: a qualitative study. Disabil Rehabil 2010; 32: 114-24.

Oshima S, Kirschner KL, Heinemann A, Semik P. Assessing the knowledge of future internists and gynecologists in caring for a woman with tetraplegia. Arch Phys Med Rehabil 1998; 79: 1270-1276.

Potter PJ, Wolfe DL, Burkell JA, Hayes KC. Challenges in educating individuals with SCI to reduce secondary conditions. Topics in Spinal Cord Injury Rehabilitation 2004; 10: 30-40.

Prabhaka MM, Thakker TH. A follow-up program in India for patients with spinal cord-injury: paraplegia safari. J Spinal Cord Med 2004; 27: 260-262.

Radomski MV, Finkelstein M, Hagel S, Masemer, S, Theis J, Thompson M. A pilot wellness and weight management program for individuals with spinal cord injury: Participants' goals and outcomes. Top Spinal Cord Inj Rehabil 2011; 17: 59-69.

Schladen MM, Libin A, Ljungberg I, Tsai B, Groah S. Toward literacy-neutral spinal cord injury information and training. Topics in Spinal Cord Injury Rehabil 2011; 16: 70-83.

Statistics Canada (2010). 2006 Participation and activity limitations survey: Disability in Canada. Ottawa: Government of Canada.

Stanley WG. Follow-up care of the spinal cord injury patient. Am Fam Physician 1981; 24: 105-111.

Starfield B. The future of primary care in a managed care era. International Journal of Health Services 1997; 27: 687-696.

Tepperman PS. Primary care after spinal cord injury. What every physician should know. Postgrad Med 1989; 86: 211-218.

Thietje R, Giese R, Pouw M, Kaphengst C, Hosman A, Kienast B, van de Meent H, Hirschfeld S. How does knowledge about spinal cord injury-related complications develop in subjects with spinal cord injury? A descriptive analysis in 214 patients. Spinal Cord 2011; 49: 43-8.

Tolbert G. Staying connected: clinicians must provide lifelong care to people with SCI. Adv Dir Rehabil 2002; 11: 23.

van Loo MA, Post MWM, Bloemen JHA, van Asbeck FWA. Care needs of persons with long-term spinal cord injury living at home in the Netherlands. Spinal Cord (online publication 3 November 2009).

Vaidyanathan S, Glass CA, Soni BM, Bingley J, Singh G, Watt J, Sett P. Doctor-patient communication: do people with spinal cord injury wish to receive written information about their medical condition from the physicians after an outpatient visit or after a readmission in the spinal unit? Spinal Cord 2001; 39: 650-653.

Van Til JA, Drossaert CHC, Renzenbrink GJ, Snoek GJ, Dijkstra E, Stiggelbout AM, Ijzerman MJ. Feasibility of web-based decision aids in neurological patients. Journal of Telemedicine and Telecare 2010; 16: 48-52.

Warms CA. Health promotion services in post-rehabilitation spinal cord injury health care. Rehabil Nurs 1987; 12: 304-308.

Weaver FM, Smith B, LaVela SL, Evans CT, Ullrich P, Miskevics S, Goldstein B, Strayer J, Burns SP. Smoking behavior and delivery of evidence-based care for veterans with spinal cord injuries and disorders. J Spinal Cord Med 2011; 34: 35-45.

Williams S. Improving the continuing care for individuals with spinal cord injuries. British Journal of Nursing 2005; 14: 161–165.

Young-Hughes S and Simbartl LA. Spinal Cord Injury/Disorder Teleconsultation Outcome Study. Rehabil Nurs 2011; 36: 153-158.

Yuen HK, Wolf BJ, Bandyopadhyay D, Magruder KM, Selassie AW, Salinas CF. Factors that limit access to dental care for adults with spinal cord injury. Special Care in Dentistry 2010; 30: 151-156.